SEED Method Toolkit: Literature Review Examples

Included examples:

- Question refinement example
- Question summary example
- Final refined research question example
- Research agenda example

Question Refinement Example

Question topic area:	**Support Systems/Coping Mechanism**

Part I: TOPIC GROUP Data	
Question(s) as posed by Topic Group: (Question 3)	**What are the factors of patient's faith (for example, knowing what happens when you die, feeling of peace or seeing family members again) and knowing family and community are praying for them; how does this affect lung cancer outcomes? Does it reduce stress and does it change your outlook?**
Outcomes of interest:	• Measurement for research: • Stress – the ability to handle challenges and physical manifestations of stress (BP, muscle tension, biomarkers • Measure of reliance on faith vs self-reliance • Length of hospitalization • Grief and family and patient
Populations of interest:	• Pastors • Congregants of faith communities • African Americans • People of Faith
Other special concerns:	Measurement of faith and support from a faith community.
Engaging Martinsville input:	Initial thoughts about this questions were : • Multiple questions in one. • Would be hard to research. • How do you measure faith? • Comparing different faiths, denominations, and their approach to activities supporting parishioners who are ill.
Quotes that help illustrate rationale and context of question:	"Knowing where you are going when you die and knowing that you are going to see family again and that they are going to see you, takes that awful grieving away. You still grieve but it's like the grieving of those that don't have that assurance, and it definitely reduces stress even though being a Christian or not when you were told you first told you had cancer, it's like, but then you, you pray and get peace." "And um, it definitely does reduces stress and it changes your outlook, because you know that whether you live or you die, you are in God's hand." "names some things that are related to faith and then wants to measure how that impacts stress and 13 is trying to hash out more of those factors of faith and how it affects lung cancer outcomes"
Key words:	**Religiosity** – broadest sense, is a comprehensive sociological term used to the numerous aspects of religious activity, dedication and belief. **Intrinsic religiousness** – religion that is an end to itself, a master motive, a framework of one's life. **Religious coping** – a means of dealing with stress that are religious. These include prayer, congregational support, pastoral care, religious faith.

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	Prayer – a request for help to God or other object of worship. **Key words** for research used: religiosity, intrinsic religiousness, religious coping, prayer, faith, outcomes, spirituality, religion, hope health outcomes, quality of life, longevity, mortality, stress, attitudes, perceptions.

Part II: Literature Review	
Studies that address the main question:	
Citation:	**Haghighi, Fatemeh. "Correlation between Religious Coping and Depression in Cancer Patients."** ***Psychiatria Danubina*** **25, no. 3 (September 2013): 236–40. (1)**
Population studied:	Descriptive-correlational study was conducted on 150 consequent cancer patients in three centers. All patients with a confirmed diagnoses of cancer.
Methodology:	Two questionnaires including Pargament's questionnaire for evaluation of religious coping and the Beck depression inventory (BDI) were used. The Religious Coping Questionnaire (RCOPE) included 20 items on a 5-point Likert scale rating which evaluated religious belief and practice including relationships with God, avoidant relationship with God and an alternately fearful and hopeful relationship.
Results/findings:	The study was carried out on 150 cancer patients and it was determined there was no significant difference between men and women in the mean score of avoidant relationship with God and alternate fearfulness and hopefulness (ambivalence coping style). The mean score of relationship with God in women was higher than men. The rate of depression was higher among patients who had an avoidant strategy. The religious coping method of relationship with God was effective in reducing depression. The rate of depression was lower among patients whose families had a better attitude to religion.
Research gaps:	Many studies have been done on religiosity and its impacts but few show definite/particular quality of life impacts. "Although, there was no relationship between positive religious coping and psychological distress, religious coping was correlated with multidimensional aspects of quality of life" (Ramirez et al. 2012)
Main take-away:	Psychotherapy, individual/familiar counseling, and especially increasing of religious beliefs such as praying and trust in God, as well as increasing the knowledge of patient and his/her family cause better acceptance of the disease and better confrontation of psychological problems.
Citation:	**Pérez, John E., and Amy Rex Smith. "Intrinsic Religiousness and Well-Being among Cancer Patients: The Mediating Role of Control-Related Religious Coping and Self-Efficacy for Coping with Cancer."** ***Journal of Behavioral Medicine*** **38, no. 2 (August 29, 2014): 183–93. doi:10.1007/s10865-014-9593-2.** **(2)**

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Population studied:	Cross sectional design of 179 ambulatory cancer patients. Participants were predominately white, Christian, and female with an average of 16 years of education.
Methodology:	179 adult cancer outpatients at three northeaster U.S. hospitals. Patients with stage II – stage IV cancer as well as advanced cancers. Patients had to be 18 years or older and in active outpatient treatment. Measures used: Demographic questionnaire, Medical chart review, Intrinsic religious motivation scale, Religious coping (RCOPE), Cancer Behavior Inventory-brief version, Functional Assessment of cancer therapy (FACT-G)
Results/findings:	"The relationship between intrinsic religiousness and well-being is fully mediated by control-related religious coping and self-efficacy for coping with cancer." Active religious surrender positively predicts self-efficacy for coping with cancer. Higher levels of self-efficacy for coping with cancer predict higher levels of the four different types of well-being. The four types of wellbeing include: physical, functional, emotional and social. "Intrinsic religiousness is the internalization of faith as the primary motive for people's lives." Several authors have fond that intrinsic religiousness is associate with better health and wellbeing. Among cancer patients, intrinsic religiousness has been positively associated with hope, meaning, and peace.
Research gaps:	There were some limitations to the study to include: non-random, clinical sample was comprised of predominately white, Christian females. They are unable to generalize the results of the study to populations that differ by race, gender, socioeconomic status and religious affiliation.
Main take-away:	The findings suggest pathways by which intrinsic religiousness and control-related religious coping are linked to various dimensions of well-being among cancer patients.
Citation:	**Gene Meraviglia, Martha. "The Effects of Spirituality on Well-Being of People With Lung Cancer."** ***Oncology Nursing Forum*** **31, no. 1 (January 1, 2004): 89–**94. doi:10.1188/04.ONF.89-94. (5)
Population studied:	60 adults ranging from 33-83 years of age. Most participants had non-small cell lung cancer and were female, Caucasian and older than 50.
Methodology:	Participants completed a questionnaire composed of six survey instruments: Life Attitude Profile, Adapted Prayer Scale, Index of well-being, Symptom distress scale and background information sheet, cancer characteristic questionnaire.
Results/findings:	Higher meaning in life scores were associated with higher psychological well-being and lower symptom distress scores. Higher prayer scores were associated with higher well-being.
Research gaps:	More research is needed on the spiritual concepts to refine framework.
Main take-away:	Spirituality and prayer have a positive effect and positive physical response which may impact lung cancer outcomes. A higher level of meaning in life showed a lower symptom distress. "Higher prayer scores are related to better well-being. Meaning in life and prayer lessen the impact of lung cancer on well-being"

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	The study finds that people with lung cancer are unique in their response to the impact for cancer. For example, people who were unmarried, in need of income to meet their daily needs, experiencing poor physical health or functional status, or currently receiving cancer treatment reported more symptom distress. The findings emphasize the importance of an individualized approach to care based on ongoing circumstances.

Studies that address outcomes of interest:	
Citation:	**Silvestri, Gerard A., Sommer Knittig, James S. Zoller, and Paul J. Nietert. "Importance of Faith on Medical Decisions Regarding Cancer Care."** ***Journal of Clinical Oncology*** **21, no. 7 (April 1, 2003): 1379–82. doi:10.1200/JCO.2003.08.036. (4)**
Population studied:	One hundred patients with advanced lung cancer, their caregivers, and 257 medical oncologist were interviewed.
Methodology:	One hundred patients with advanced lung cancer, their caregivers, and 257 medical oncologist were interviewed. Participants were asked to rank importance of the following factors that might influence treatments decisions: cancer doctor's recommendation, faith in God, ability of treatment to cure disease, side effects, family doctor's recommendations, spouse's recommendations and children's recommendations.
Results/findings:	All three groups ranked the oncologist recommendation as most important. Patients and caregivers ranked faith in God second, whereas physicians placed it last.
Research gaps:	Future studies need to clarify HOW faith influences decision making. One major limitation is that all patients and interviews were from participants that were from the bible belt. This could potentially affect the results by not including a diverse religious group.
Main take-away:	"Patients and caregivers agree on the factors that are important in deciding treatment for advanced lung cancer but differ substantially from doctors. All agree that the oncologist's recommendation is most important. This if the first study to demonstrate that, for some, faith is an important factor in medical decision making, more so than even the efficacy of treatment. In faith plays an important role in how some patients decide treatment, and physicians do not account for it, the decision making process may be unsatisfactory to all involved." Medical decision making can certainly affect outcomes for the patient, therefore making a correlation between faith – decision making – outcomes. The authors feel this is the report regarding the difference of how physicians, caregivers and patients view influences of medical decision making.
Citation:	**Juliana, Franceschini, José R. Jardim, Ana Luisa Godoy Fernandes, Sérgio Jamnik, and Ilka Lopes Santoro. "Reliability of the Brazilian Version of the Functional Assessment of Cancer Therapy-Lung (FACT-L) and the FACT-Lung Symptom Index (FLSI)."** ***Clinics (Sao Paulo, Brazil)*** **65, no. 12 (2010): 1247–51. (6)**

Question Refinement Example

Population studied:	30 patients with lung cancer were recruited from an outpatient lung cancer clinic.
Methodology:	The FACT-L with the FLSI questionnaire was prospectively administered to 30 consecutive, stable, lung cancer patients.
Results/findings:	The FACT-L with FLSI questionnaire is reliable, quick and simple to apply. The instrument can be used to evaluate the quality of life of Brazilian lung cancer patients.
Research gaps:	Translation of the FACT to other languages
Main take-away:	The primary purpose of the study was to review the reliability of the FACT-L assessment in conjunction with the FACT-Lung Symptom Index questionnaire to prove quality of life. This assessment could potentially be used with the spiritual assessments to evaluate lung symptoms and prove quality of life either being better or worse. Quality of life has become an important aspect for *clinical trials* and important research agenda to prove or not that spirituality does improve the quality of life.

Citation:	**Monod, Stéfanie, Mark Brennan, Etienne Rochat, Estelle Martin, Stéphane Rochat, and Christophe J. Büla. "Instruments Measuring Spirituality in Clinical Research: A Systematic Review." *Journal of General Internal Medicine* 26, no. 11 (November 2011): 1345–57. doi:10.1007/s11606-011-1769-7. (7)**
Population studied:	35 instruments were used to measure spirituality in clinical research. The literature search initially began with 1575 citation and were narrowed down to 35 instruments. The instrument was validated in the largest and most diverse population by using 5087 participants in 18 countries through the World Health Organization.
Methodology:	A systematic search in MEDLINE, CINHAL, psycINFO, ATLA and EMBASE databases using terms such as "spirituality"
Results/findings:	Thirty five instruments were classified into measure of spirituality (22), spiritual well-being (4), spiritual coping (4), and spiritual needs (4). The instruments that are most frequently used are the FACIT-SP and Spiritual Well-being scale.
Research gaps:	The study also highlights the absence of instruments to measure poor spiritual well-being
Main take-away:	This review provides details on instruments that assess spirituality and the relationship between spirituality and health. The first reaction of the research team members and the topic group members was that no one could imagine there would be measurement tools for spirituality. The research question is one that one would think was open ended and did not have the ability to connect with other assessments to prove or disprove the connection of spirituality (prayer) and outcomes. After the literature review, it is clear that many have interest in the relationship between spirituality and well-being – therefore resulting in good outcomes but have had some challenges to try to use the appropriate/effective tools to create a constructive and concrete way of evaluating the two to prove results. Much research is still to be done

	regarding this relationship. More research is needed on the relationship of spirituality and wellbeing.

Citation:	**Smith, Amy Rex, Susan DeSanto-Madeya, John E. Pérez, Elizabeth F. Tracey, Susan DeCristofaro, Rebecca L. Norris, and Shruti L. Mukkamala. "How Women with Advanced Cancer Pray: A Report from Two Focus Groups."** ***Oncology Nursing Forum*** **39, no. 3 (May 1, 2012): E310-316. doi:10.1188/12.ONF.E310-E316. (8)**
Population studied:	13 adult females outpatients receiving active treatment for ovarian or lung cancer.
Methodology:	Two focus groups were conducted with data coding and analysis using standard procedures.
Results/findings:	"Four themes emerged: finding one's own way, renewed appreciation for life, provision of strength and courage, and gaining a stronger spiritual connection. In addition, praying for others, conversational prayer, petition prayer, ritual prayer and thanksgiving prayer were used most often by participants to cope.
Research gaps:	There is research on hope and wellbeing with many types of cancer; however there is limited research on spirituality and lung cancer.
Main take-away:	The findings support that prayer is a positive coping mechanism. The goal was to look at the meaning of prayer and identify the effects that it has. In conclusion of the focus groups, it was identified that prayer was an important factor for coping in cancer diagnosis.

Citation:	**Lissoni, P., G. Messina, D. Parolini, A. Balestra, F. Brivio, L. Fumagalli, L. Vigore, and F. Rovelli. "A Spiritual Approach in the Treatment of Cancer: Relation between Faith Score and Response to Chemotherapy in Advanced Non-Small Cell Lung Cancer Patients."** ***In Vivo (Athens, Greece)*** **22, no. 5 (October 2008): 577–81. (12)**
Population studied:	50 consecutive patients who were suffering from metastatic non-small cell lung cancer.
Methodology:	A clinical approach to investigate spiritual faith.
Results/findings:	The study suggest that there is evidence of a "high degree of faith as an expression of an active spiritual life was associated with a greater efficacy of cancer chemotherapy and may predict a longer survival in metastatic cancer patients." The study suggest that the positive influence of spiritual faith in patients who were receiving chemotherapy vs those without faith.
Research gaps:	This study was specific to non-small cell lung cancer with metastatic disease.
Main take-away:	The preliminary study suggest that evidence of a high degree of faith as an expression of an active spiritual life was associated with great efficacy of cancer treatment and may predict a longer survival rate. This study was directly focused on lung cancer and could possibly be used for other types of cancer. The study did emphasis the importance faith has and the influencing factors on neoplastic disease. Further

	research will be needed in a greater number of patients to confirm the data.

Studies that address specific populations of interest:	
Citation:	**Achour, Meguellati, Fadila Grine, Mohd Roslan Mohd Nor, and Mohd Yakub Zulkifli MohdYusoff. "Measuring Religiosity and Its Effects on Personal Well-Being: A Case Study of Muslim Female Academicians in Malaysia."** ***Journal of Religion and Health*** **54, no. 3 (April 27, 2014): 984–97. doi:10.1007/s10943-014-9852-0. (3)**
Population studied:	315 Muslim female of academic staff as respondents working in Research Universities.
Methodology:	Data was completed by 450 female academic staff working in Research University in Klang Valley. A total of 315 questionnaires were returned with a response rate of approximately 70%. The ages of the respondents ranged from 30-60 years.
Results/findings:	A positive and significant correlation between personal well-being and religiosity. Well-being shows significant positive correlations with beliefs and worship.
Research gaps:	The article does not address lung cancer impacts/outcomes. The emphasis is primarily on correlation of faith and well-being. Many research projects have been done regarding faith and well-being but more research needs to be done in different religious sectors and correlation of impacts on patients with cancer.
Main take-away:	A positive correlation of faith, prayer and religiosity affecting overall well-being of women in the Muslim faith. If it creates a positive correlation in life overall, would it continue in tragedies of life, cancer diagnosis and other challenges faced in life.
Citation:	**Rawdin, Blake, Carrie Evans, and Michael W. Rabow. "The Relationships among Hope, Pain, Psychological Distress, and Spiritual Well-Being in Oncology Outpatients."** ***Journal of Palliative Medicine*** **16, no. 2 (February 2013): 167. doi:10.1089/jpm.2012.0223. (9)**
Population studied:	78 patients who were care in a comprehensive oncology center.
Methodology:	Patients were recruited from a Symptom Management Service (SMS) who were 18 years of age or older who had a diagnosis of cancer.
Results/findings:	95 patients were approached and 78 agreed to participate. The sample consisted of 64% women and 36% men with a mean age of 57.6 years. Levels of hope were not associated with age, gender or the presence of metastatic disease. This study was performed due to the lack of research on the relationship between hope and pain among cancer patients. The findings suggest that hope is related most closely to psychosocial elements of the pain experience, rather than pain intensity. "hope is a key clinical and perhaps therapeutic variable, affecting cancer patients"
Research gaps:	Lack of causal relationships between hope and pain. The limitations were that the study was cross sectional and it would be ideal if there

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	was a longitudinal study between causal links between hope, pain, and psycho-spiritual factors.
Main take-away:	The study suggest "that when confronted with a patient who seems to have "lost hope," the physician should look beyond pain measures and explore psychological adjustment and spiritual concerns.

Studies that address patients with/at risk for lung cancer.	
Citation:	**Clay, Kimberly S., Costellia Talley, and Karen B. Young. "EXPLORING SPIRITUAL WELL-BEING AMONG SURVIVORS OF COLORECTAL AND LUNG CANCER."** ***Journal of Religion & Spirituality in Social Work*** **29, no. 1 (January 1, 2010): 14–32. doi:10.1080/15426430903479247. (10)**
Population studied:	800 survivors was drawn from the Alabama CanCORS cohort, who had a diagnosis of cancer, less than one year post treatment, 18 years or older, able to read and write English, had completed the CanCors baseline questionnaire.
Methodology:	The survey was mailed to potential participants. Of the 800 surveys, 343 (43%) were completed and returned. Spiritual well-being was measured using an expanded version of the FACIT-SP.
Results/findings:	The purpose of the study was to characterize spiritual well-being in newly-diagnosed survivors of colorectal and lung cancer. The study found that spiritual well-being scores were high across both colorectal and lung cancer survivors. There is some question of defining a lung cancer survivor regarding survivorship as "the period extending from the time of diagnosis throughout the balance of life"
Research gaps:	Limitation included a cross-sectional descriptive, correlation design which only identifies asocial of a specific point in time. The study did not attempt to address or control potential self-selection vias, where differences may exist between those who volunteered and those who refused participation in the study. There are some studies that have been done to link spiritual well-being and breast cancer survivorship, there are no published studies of the examination among colorectal and lung cancer. The lack of adequate and accurate data on colorectal and lung cancer survivors and quality of outcomes must be addressed because of the significant incidence they both account for.
Main take-away:	Future research is needed on survivors of colorectal or lung cancer and spiritual-based therapeutic and lifestyle interventions must be developed to potentially treat or ameliorate the physiologic and psychosocial late effects of cancer in general. The overall finding states a significant need for oncology and social workers to assess spiritual well-being in cancer survivors to strengthen treatment plans, which can change outcomes.
Citation:	**Steinhauser, Karen E., Stewart C. Alexander, Ira R. Byock, Linda K. George, Maren K. Olsen, and James A. Tulsky. "Do Preparation and Life Completion Discussions Improve Functioning and Quality of Life in Seriously Ill Patients? Pilot Randomized Control Trial."**

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	***Journal of Palliative Medicine* 11, no. 9 (November 2008): 1234–40. doi:10.1089/jpm.2008.0078. (11)**
Population studied:	82 hospice eligible patients enrolled in the study: 38 were women and 35 were African American.
Methodology:	Baseline measurement assessed pain and symptoms, functional status, anxiety, depression, quality of life at the end of life, and daily spiritual experience.
Results/findings:	Participants in the active discussion showed improvements in functional status, anxiety, depression and preparation for end of life. The study concluded that patient emotional and spiritual well-being were identified as part of two larger domains: end of life preparation and completion.
Research gaps:	50% of the participants were not able to complete the study due to functional decline or death. Sample size was not large enough to show statistical significance.
Main take-away:	A concept model was created and show that patients living with advanced serious illnesses face challenges associated with physical, psychosocial, spiritual, and emotional concerns. Attention to these is required to reduce suffering and increase quality of life.

Studies that address any other special concerns:	
Citation:	**Granero-Molina, J., M.m. Díaz Cortés, J. Márquez Membrive, A.m. Castro-Sánchez, O.m. López Entrambasaguas, and C. Fernández-Sola. "Religious Faith in Coping with Terminal Cancer: What Is the Nursing Experience?" *European Journal of Cancer Care* 23, no. 3 (May 1, 2014): 300–309. doi:10.1111/ecc.12150. (13)**
Population studied:	23 nurses who had cared for people with terminal cancer for at least six months.
Methodology:	A qualitative approach. The participants were nurses, Masters in Nursing.
Results/findings:	The statements in the students were that faith in relation to end-of-life was apparent. Traditional faith and religious beliefs continue to be an important aspect in relation to end-of-life. The goal of the study was to understand how significant faith is during the end-of-life process.
Research gaps:	Research shows that faith in coping is essential but is individualized and changeable. "Some studies have found a correlation between faith and finding peace and a meaning to life for cancer patients" The need for a larger review of nurses who were unaware of the study and also include a better selection of nurses who's age ranges will give a better source of information towards the study.
Main take-away:	Knowledge by the nursing staff of knowing how important spirituality is can help to improve the quality of life for individuals with a terminal cancer diagnosis. Three main themes: Faith facilitates the coping process – "faith can help to give meaning to the dying process, giving answer in the search for reason of existence." Faith hinders the cooping process – some participants will reflect on divine punishment; therefore hindering the coping process. The

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	patients feel they are being punished by God for certain habits or life situations. Guild can cause some spiritual suffering for patients. Terminal illness impacts faith – Terminal illness can affect patients and families differently ton include doubting faith, strengthening faith and even abandoning faith. Anger can take over and cause abandonment in their faith and family due to overwhelming feelings of resentment and abandonment from God.

Part III: Summary of the Literature	
What we know	**What we need to know more about**
Research on the main question	
There are spiritual tools to assist with measuring spirituality. These tools are also taken with other tools such as FACT-L tools to evaluate quality of life. In conjunction we are able to assess spirituality and increase/decrease of quality of life. This tool is reliable, quick and simply to apply. There are so many measurement tools that it is difficult to address which one is the most affective and accurate.	Little is known about the outcomes specifically regarding lung cancer. How does early/late detection factor into the connection of spirituality and quality of life/outcomes.
Religious coping is effective with reducing depression and that depression was lower among patients whose family members had a better attitude and connection with faith.	What aspects of family members connection with faith directly impacts patients with lung cancer. What attributes to the lowering of depression?
Active religious surrender affects coping with cancer	What coping skills are directly affected? What types of cancer are going to reflect this statement due to the fact that different cancers offer different responses from their patients? Lung cancer is typically found in late stage and the coping mechanism may not be the same as one diagnosed with a cancer that is early and considered non-life threatening.
Higher prayer is associated with higher well being	Does well being differ in patients with different cancer diagnosis? For example, breast vs lung or colon vs lung or bladder vs lung?
Research on outcomes of interest	
Quality of life indicators can be vastly different per individuals. Lung Cancer offers a different set of issues because of the expected high mortality rate; therefore causing individuals to experience fear and apprehension immediately in the initial diagnosis stage.	More research regarding standards that outline quality of life indicators for lung cancer patients. Lung cancer patients present with different barriers that most cancer diagnosis due to breathing issues causing anxiety and stress. Also, lung cancer patients are typically diagnosed at a later stage; therefore creating more anxiety facing the terminal disease and prognosis.

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Research on populations of interest	
Cancer in general has been researched in connection with spirituality/quality of life/outcomes	Which populations are most impacted? Are their particular religious sectors that provide more/less quality of life outcomes?
Research on patients with/at risk of lung cancer	
Specific studies for lung cancer are limited. This is due to some studies being incomplete due to lack of interest, length of study,	Does a lung cancer diagnosis fall within the realms of other cancer diagnosis due to the fact that it does have a high mortality rate and also physical complications create more barriers for patients with coping and wellbeing?
Research on any other specific concerns	
Studies on religious coping, religiosity, effects of spirituality, measurement tools (numerous), well-being, end of life with lung cancer.	Are there any particular tools that are more effective when measuring these?
	How can increasing focus on spirituality increase patients to choose care at facilities who provide this service – spirituality, counseling, support groups. (The increase of patients choosing facilities who offer these services may cause facilities to focus on providing these to increase revenue – this could be a winning situation for patients who are in rural areas that are going outside of the area because of perceived "better services")
	Typically there are differences of how physicians assess spirituality and its importance. Continued education of support of patients from a spiritual aspect to cross over to providers, nursing, social workers and others who are providing caregivers to lung cancer patients.
	How do you measure poor spiritual wellbeing?
	How would clinical investigations on spiritual faith affect the concept and application of these tools affect lung cancer patients wellbeing? If clinical providers acknowledged and accepted spiritual effects on patient outcomes, would they be more willing to adopt these practices in their daily treatment plans.

Part IV: Where are the research gaps? (Fill in where relevant)	
Substantive (e.g., Patient perceptions/knowledge, clinical care, interventions, outcomes (including long term outcomes), comparative effectiveness, communication/education, policy)	Long term studies are typically not available. Many participants are unable to finish studies due to declining health or death.
Methodological (e.g., study design and methods)	Most studies include questionnaires.

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Population (e.g., Race, socioeconomic status, health status, geography, age, vulnerable populations, workers)	Available participants that cover a multi-cultural group. Age gaps and inconsistent age gaps. Typically more female participants than male.

Suggested Re-wording of research questions:
Research Questions :
1. How does faith affect a lung cancer patient's decisions about their clinical care?
2. How does faith affect a lung cancer patients outcomes vs a lung cancer patient without faith?
3. What specific lung cancer outcomes are affected by Faith?
4. Does faith reduce stress and improve survival of lung cancer patients?
Research Questions (after groups feedback)
1. How does faith affect a lung cancer patient's decisions about their clinical care?
2. How does faith affect a lung cancer patients outcomes vs a lung cancer patient without faith?
3. What specific lung cancer outcomes are affected by faith?
4. Does faith reduce stress and improve survival of lung cancer patients?
Final Research Questions (after VCU feedback)
1. How does religious faith affect lung cancer patients' decision making about their treatment options and health care?
2. How do patient lung cancer outcomes differ between people with and without faith?
3. What health and quality of life outcomes are impacted by religious faith among patients with lung cancer, including stress and survivorship?

Question Refinement Summary Example

Question(s) as posed by Topic group:	**What are the factors of patient's faith (for example, knowing what happens when you die, feeling of peace or seeing family members again) and knowing family and community are praying for them; how does this affect lung cancer outcomes? Does it reduce stress and does it change your outlook?**
Outcomes of interest:	• Measurement for research: • Stress – the ability to handle challenges and physical manifestations of stress (BP, muscle tension, biomarkers • Measure of reliance on faith vs self-reliance • Length of hospitalization • Grief and family and patient
Populations of interest:	• Pastors • Congregants of faith communities • African Americans • People of Faith
Other special concerns:	Measurement of faith and support from a faith community.
Engaging Martinsville input:	Initial thoughts about this questions were : • Multiple questions in one. • Would be hard to research. • How do you measure faith? • Comparing different faiths, denominations, and their approach to activities supporting parishioners who are ill.

Literature Reviewed
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Suggested Re-wording of research questions:
Research Questions :
1. How does faith affect a lung cancer patient's decisions about their clinical care?
2. How does faith affect a lung cancer patients outcomes vs a lung cancer patient without faith?
3. What specific lung cancer outcomes are affected by Faith?
4. Does faith reduce stress and improve survival of lung cancer patients?
Research Questions (after groups feedback)
1. How does faith affect a lung cancer patient's decisions about their clinical care?
2. How does faith affect a lung cancer patients outcomes vs a lung cancer patient without faith?
3. What specific lung cancer outcomes are affected by Faith?
4. Does faith reduce stress and improve survival of lung cancer patients?
Final Research Questions (after VCU feedback)
1. How does religious faith affect lung cancer patients' decision making about their treatment options and health care?
2. How do patient lung cancer outcomes differ between people with and without faith?
3. What health and quality of life outcomes are impacted by religious faith among patients with lung cancer, including stress and survivorship?

Final Refined Research Questions - Example

Please see below for an example from the Martinsville, VA demonstration.

Question category: Social
1. How does religious faith affect lung cancer patients' decision making about their treatment options and health care? ➢ How do patient lung cancer outcomes differ between people with and without faith? ➢ What health and quality of life outcomes are impacted by religious faith among patients with lung cancer, including stress and survivorship?

Patient and Stakeholder Developed Research Agenda – Diabetes/Hypertension Management

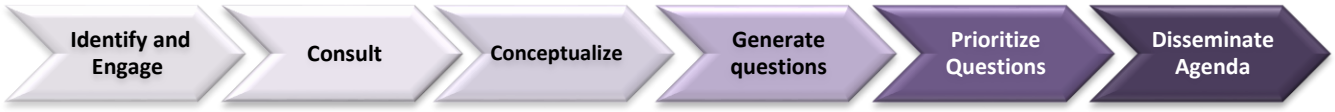
The **SEED** (Stakeholder Engagement in quEstion Development and prioritization) **Method** is a new stakeholder engagement methodology that combines engagement with a review of available evidence to generate research questions that address current research gaps that are important to patients and other stakeholders.

The first demonstration of the SEED Method took place during 2015 in Richmond, VA in a primarily low-income, urban, African American community. The health topic of focus was diet and behavioral management for diabetes and hypertension.

Stakeholder engagement: The SEED Method allowed stakeholders to participate through three different modes of engagement: collaborative, participatory, and consultative.

> **Collaborative engagement:** This level of engagement consisted of a research team derived from an existing community-university partnership made up of academic faculty, staff, and community residents. The Research Team was engaged throughout the project and were responsible for selecting and recruiting participants, data collection and analysis, and facilitation of Topic group meetings and activities.
>
> **Participatory engagement:** This level consisted of groups of stakeholders (Topic groups) selected by the research team based on their experience with and knowledge of diet and behavioral challenges in diabetes and hypertension management. Three groups of stakeholders were convened to participate in a series of meetings that resulted in the development and prioritization of research questions. The groups included: 1) seniors with diabetes or hypertension who were overweight or had cardiovascular disease (n=8), 2) adults with diabetes or hypertension with limited health care access of other specific challenges (e.g. history of homelessness or substance use) (n=7), and 3) nurses, health educators, and other local services providers (n=8).
>
> **Consultative engagement:** To broaden the Topic groups' understanding of the experiences of different stakeholders, this level of engagement consisted of focus groups and one-on-one interviews. Five focus groups were conducted, composed of: African American females, seniors, food pantry clients, Supplemental Nutrition Assistant Program (SNAP) recipients, and people taking medications for diabetes and hypertension. Eleven interviews were conducted with health care workers, service providers, and parents of children with diabetes.

SEED Methodology: The SEED Method followed a six-step process that included 1) identifying the health topic and recruiting participants, 2) conducting focus groups and interviews, 3) developing conceptual models, 4) developing research questions, 5) prioritizing research questions, and 6) creating a dissemination plan and distributing the final research agenda.



Patient and Stakeholder Developed Research Agenda – Diabetes/Hypertension Management

Development of Research Agenda: In total 18 research questions were prioritized by the Topic groups. Each question was researched and finalized by a review team of VCU researchers through a review of the scientific literature. The review explored what parts of each question had already been answered by prior studies and made recommendations to get at issues that remain unanswered empirically. Based on the review conducted for each question, the review team made recommendations to address relevant gaps in the peer reviewed literature. As a final step, research and subject matter experts were consulted on each finalized questions for feedback on the wording of the recommendations and to ensure their relevance to their respective fields of study.

Patient and Stakeholder Developed Research Topics Related to Diet and Behavioral Management for Diabetes and Hypertension (Reprinted with permission from the American Journal of Preventive Medicine)

Risk factors and health behaviors

1. Does a person's **functional capacity** (physical and cognitive) influence their ability to follow their diet?
   - ❖ Among people with diabetes or hypertension, how do functional capacity (physical and cognitive) and geriatric conditions (such as visual impairment, mobility) impact the ability to follow dietary recommendations?
   - ❖ How and why does a person's functional capacity influence their ability to follow the recommended diet for diabetes and hypertension?
   - ❖ What are the long-term diabetes and hypertension-related health outcomes for people with limited functional capacity or geriatric conditions?

2. What is the impact of **drug and alcohol use** on diet compliance?
   - ❖ What are optimal and practical ways to screen for co-morbid substance abuse disorder in patients with diabetes or hypertension?
   - ❖ Can health care providers use information on type and frequency of substance use to inform dietary recommendations?
   - ❖ What is the efficacy and cost-effectiveness of substance abuse screening, brief intervention, and referral to treatment (SBIRT) in improving outcomes for individuals with coexisting substance use disorder and diabetes?
   - ❖ What is the comparative effectiveness of different interventions that integrating SBIRT for alcohol and other drug use problems into diabetes care models?

3. Do **cognitive impairment and dementia** impact self-care behaviors and health outcomes in people with diabetes and hypertension?
   - ❖ At what levels and domains of cognitive impairment are patients most likely to become at risk of non-adherence to diabetes self-care management?

Patient and Stakeholder Developed Research Agenda – Diabetes/Hypertension Management

- ❖ What are the healthcare needs and goals of patients with cognitive impairment and diabetes and what are the needs of their caregivers? How are these different from the needs of patients without cognitive impairment?
- ❖ What are the most effective strategies for successfully managing both cognitive impairment and diabetes?

4. Does not having enough **sleep** affect diet for people with diabetes and hypertension, and how do specific sleep patterns affect diet?
   - ❖ What are the current levels of patients' knowledge, perceptions and understanding of the relationship between sleep and health outcomes related to diabetes and hypertension?
   - ❖ Are health care providers regularly and effectively communicating with patients about the impact of sleep duration on weight, glucose control, diabetes risk and hypertension?
   - ❖ Which interventions can improve sleep duration among patients with diabetes or hypertension? What is the effectiveness among at risk populations, including African Americans, shift workers, younger, and low-income groups?
   - ❖ What communication strategies or tools can improve patient-centered information about the risk of insomnia and changes in sleep patterns related to anti-hypertensive agents and other drugs for hypertension or diabetes?

Health care communication/knowledge and perceptions

5. What strategies are available to identify and enhance patients' **sense of control** related to following the recommended diet?
   - ❖ What is the comparative effectiveness of interventions for increasing patients' empowerment and improving dietary compliance over time? (Strategies include empowerment-based diabetes self-management education programs; web-based tools and social media)
   - ❖ How can interventions for empowering patients be incorporated into different clinical settings?

6. If mental health patients were given **nutrition guidelines and information**, would it affect overall health?
   - ❖ What strategies and interventions are most effective in improving the diet and nutrition of people with severe mental illnesses, particularly those who continue to have uncontrolled diabetes or hypertension?
   - ❖ What strategies and interventions are most effective in improving the diet and nutrition for elderly patients with severe mental illnesses?
   - ❖ Which health professionals or service providers are best able to assist patients with severe mental illness, especially those navigating multiple systems and medication routines?

7. Will controlling diabetes and hypertension **prevent other diseases** or more serious illness?
   - ❖ What are the most effective strategies for communicating risk of complications to patients with diabetes or hypertension?

Patient and Stakeholder Developed Research Agenda – Diabetes/Hypertension Management

- ❖ What are the most effective strategies for communicating risk information among special populations, such as patients with low health literacy, low income, and elderly patients and are they being used in care settings?
- ❖ How do patients' understanding of risk information and related health beliefs predict clinical outcomes and development of complications?
- ❖ What is the effect of diabetes combined self-management education and training (DSME/T) on clinical outcomes and development of complications?

8. How does **knowing about your diet and risks** help with understanding diabetes?
   - ❖ What are the strongest influences on patient perception (knowledge, understanding, attitudes) of diabetes, and what are the best practices for altering perceptions that prevent effective disease management?
   - ❖ What are the most effective strategies for integrating nutrition education into regular diabetes care administered by health professionals to improve diet?
   - ❖ How does patient perception of diabetes differ by age and health literacy?

9. How could provider/patient communication about the **science of nutrition and exercise** be simplified and made more interactive?
   - ❖ How can nutrition and physical activity counseling in primary care be improved and made more understandable for patients?
   - ❖ What strategies and messages are being utilized during a primary care visit or over a course of visits? How can messages be tailored to the health literacy, cultural context, and motivation of individual patients?
   - ❖ What is the comparative effectiveness of different nutrition counseling strategies in patient uptake and outcomes? What about physical activity counseling?
   - ❖ What are effective strategies for combining primary-care based counseling with follow up interventions and access to information (e.g., telephone, web and text-based delivery) and getting those services reimbursed?

Health care delivery and quality

10. Will having a **regular doctor** improve diabetes and hypertension self-management?
    - ❖ What factors affect the relationship between having a regular doctor and patient-centered health outcomes among patients with diabetes and hypertension? What is the role of race/ethnicity, mental health conditions, and low socioeconomic status?
    - ❖ What are the most effective strategies for arranging a regular doctor for patients with diabetes/hypertension, including patients with mental health challenges, with a regular care provider or medical home?

11. How are healthcare quality and **trust in one's doctor** related, and how does that impact diabetes and hypertension management?

Patient and Stakeholder Developed Research Agenda – Diabetes/Hypertension Management

- How does continuity of care impact patient trust in patients with diabetes/hypertension who are uninsured or have limited access to care? What are the best strategies for increasing continuity of care in this population?
- What aspects of care continuity predict patient trust and improved health outcomes?
- What are the most effective interventions for increasing patient trust, especially among vulnerable populations?

12. Would communicating with your primary care provider for **longer periods of time** during a given visit lead to better prioritizing and self-management behavior for diabetes and hypertension?
    - How does the length of consultation with primary care physicians impact self-management behaviors and clinical outcomes in patients with diabetes and hypertension? Does an increase in appointment length lead to improved clinical outcomes and patient self-management behaviors?

Health economics

13. How does the inability to pay an **insurance co-payment** affect your health care?
    - How does cost sharing affect health care utilization for patients with diabetes or hypertension who have low- and very low incomes, including those who are food insecure?
    - Among people with diabetes or hypertension, what types of health care services are reduced as a result of cost sharing?
    - How do long-term health outcomes of people with diabetes or hypertension differ with cost sharing versus those not subject to cost sharing?
    - What is the impact on health care utilization and health outcomes of programs that reduce or cap cost sharing among vulnerable low-income groups? What is the impact by race/ethnicity?
    - How do co-payments affect health care utilization decisions, including patient perceptions, knowledge, preferences, strategies and the impact of competing needs? How do patients describe the impact of co-payments on these decisions and strategies?

Policy

14. How is the amount of **Supplemental Nutrition Assistance Program (SNAP) benefits** determined for those who qualify and how does that match up with need?
    - How can SNAP qualifications and benefit levels be adjusted to reflect the needs of individuals with chronic, diet-sensitive conditions?
    - How can the SNAP program work with individuals with diet-sensitive conditions to improve diet quality and diabetes self-management?
    - What is the risk, based on longitudinal data, for negative health outcomes among food insecure individuals with (or at risk of) diabetes or hypertension? What role do SNAP benefits play in mitigating negative outcomes?

15. How could we encourage communities to focus on **economic development** in high risk areas to have the highest impact on dietary compliance?

Patient and Stakeholder Developed Research Agenda – Diabetes/Hypertension Management

- ❖ What is the impact of local food initiatives (urban agriculture, community supported agriculture (CSA's), farmers markets, community gardens, farm to school/institution) on local economies, jobs, income supplementation, workforce integration, and social capital development?
- ❖ Do local food initiatives improve food security, diet quality and long-term health outcomes of individuals with diabetes or hypertension?
- ❖ How effective are incentive programs such as farmers market vouchers and other interventions (e.g., food demonstrations and educational initiatives) at increasing the impact of local food initiatives on diet quality for individuals with diabetes or hypertension in low-income or food insecure households?

Physical and social environment

16. What role does **food** play in one's family and upbringing, and how does that affect individuals' relationship with food as adults?
    - ❖ What culturally-sensitive strategies are effective in changing social norms around eating and in achieving long-term behavior change and healthy eating?
    - ❖ Can programs that adapt culturally preferred foods into healthy eating plans affect diet compliance for people with diabetes or hypertension?
    - ❖ Is healthy eating affected more by personal preferences and social norms or by the availability of household/community resources on healthy eating? How does knowledge of healthy eating mediate those relationships?

17. How does the local **environment**, such as access to stores, affect the diet of people with diabetes or hypertension?
    - ❖ For those with diet-restricting conditions (ex. hypertension and diabetes), what role does the food environment play in individual's ability to adhere to diet? How do individuals adapt to or navigate their existing food environment to meet their dietary needs or goals?
    - ❖ How can small food retailers and others in adverse food environments be better engaged to carry and promote healthier food options?
    - ❖ What role can community organizations and businesses play in promoting healthier food choices or change in the local food environment?

18. How does lack of **transportation** affect the likelihood of seeking medical treatment, resources, and services among individuals with diabetes and hypertension?
    - ❖ What interventions by communities, health service providers, and health systems to reduce transportation barriers positively impact service usage those living with chronic conditions?
    - ❖ Are telemedicine and internet enabled home-based care viable (in terms of cost, feasibility, and effectiveness) alternatives to regular outpatient diabetes or hypertensive care among those who lack transportation?
    - ❖ For patients with chronic diseases, how do transportation barriers vary across urban, suburban, or rural areas?
    - ❖ Do transportation-only interventions improve treatment compliance among patients with multiple challenges or needs?